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Upcoming MG Walks

- San Diego, CA – 5/1/2015
- Green Bay, WI – 5/9/2015
- Greenfield, WI – 5/9/2015
- Manhattan, NY – 5/30/2015
- Boston, MA – 6/6/2015
- New Haven, CT - 6/6/2015
- Cohoes, NY – 6/7/2015
- Tulsa, OK – 6/13/2015
- Naperville, IL – 9/27/2015
- Spearfish SD – 10/17/2015
- Aurora, CO – 10/18/2015

Facebook.com/MGWalks
Twitter.com/MG_Walk



Top 10 Things to Do During June Awareness Month

The month of June is MGFA's official "MG Awareness Month." The national office along with chapters, support groups and individuals throughout the country, are involved in a variety of activities to promote awareness. Below are the Top 10 things you can do to help promote MG Awareness Month. Please note that this Top 10 list is not necessarily in order of importance or priority, but participating in these activities, not only throughout the month, but year-round, will help us raise MG awareness and research funds to find a cure.

1. Write to Elected Officials about MG – Many support groups and chapters have succeeded in recent years in contacting their local officials making them aware that June is Myasthenia Gravis Month. As a result, they have gained MG Awareness Month Proclamations in their respective cities. Send a note to state and national elected officials. Tell them about MG and patient and caregiver needs. Write your congress person advocating for an increase in federal funding to find a cure for MG, neuromuscular and autoimmune diseases as well as other orphan diseases. *Continued on page 3*

My Journey as a Myasthenia Gravis (MG) Care Giver

My name is Herb Johnson and my MG journey began in May, 2009 when my wife Dorothy's symptoms, droopy eyes, double vision, trouble swallowing and breathing, and general arm/leg muscle weakness were diagnosed as MG. I'm sure many of you understand the process as you have been there.

I immediately put my newly found retirement on the back burner and became a caregiver to my angel of a wife, Dorothy whom I love dearly and who is my 'rock' in our 30+ years second marriage - she has to be, to put up with me. She also keeps me grounded in understanding the difference between having MG and being a caregiver, relative or friend who just understands MG. *Continued on page 4*

WALK A DAY IN OUR SHOES
MYASTHENIA GRAVIS = GRAVE MUSCLE WEAKNESS, AKA MG

Looks can be deceiving; people with Myasthenia Gravis, an autoimmune neuromuscular disease, often look normal to others even while they may be suffering in many ways. More than 100,000 people of all ages, races and genders, are coping every day with the debilitating and potentially life-altering effects of MG.

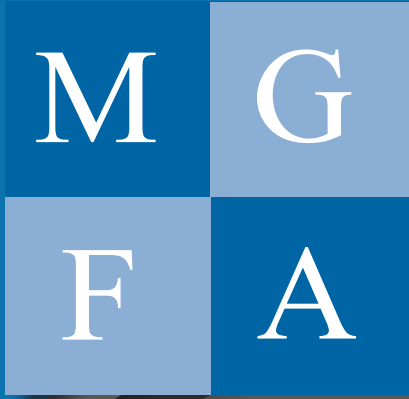
PROUD TO CELEBRATE MYASTHENIA GRAVIS AWARENESS MONTH

M G MYASTHENIA GRAVIS
F A FOUNDATION OF AMERICA, INC.®

TROUBLE CHEWING **WADDLING GAIT**
DROOPY EYELIDS **DIFFICULTY BREATHING**
CAN'T SMILE **SLURRED SPEECH**
MUSCLE WEAKNESS **DOUBLE VISION**
BLURRY VISION **TROUBLE SWALLOWING**

TO LEARN MORE ABOUT MG AND HOW YOU CAN HELP, VISIT ONLINE AT WWW.MYASTHENIA.ORG OR CALL 1-800-541-5454.

The 2015 June MG Awareness Month Poster sent to Chapter and Support Group Leaders in late April 2015. To get a copy please call the MGFA National Office at 800-541-5454.



Message from Chairman Sam Schulhof

This is my last letter to you as Chairman of the Foundation as my term of office ends at the conclusion of this year’s National Conference. I want to thank you for affording me the honor of serving as a member of the MGFA board of Directors for the last eleven years and as Chair of the Foundation’s Board of Directors for the past ten of those.

During my tenure I have had the opportunity to meet and work with some truly great people... patients, caregivers, doctors and nurses... and all of the many volunteers who have made and will continue to make MGFA a vital part of our vision of “A World Without MG.”

John Adams once said: “to be good, and to do good, is all we have to do.” For MGFA’s volunteer board, professional staff and the many other volunteers across this country, the number one priority has

always been and always will be the organization’s mission. However, the ability “to do good” has never been more challenging.

The responsibility of balancing MGFA’s ability to meet current and changing needs of the community while managing the risks involved continues to grow more complex. Yet, our commitment remains strong, our mission guides us and the MG community is a family that sustains us.

As Thomas Jefferson said, “I like the dreams of the future better than the history of the past.” As I leave the Chairmanship of MGFA, I share that optimism and look forward to watching MGFA become an even more important and vital part of the MG community.

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Top 10 Things to Do During June Awareness Month

2. Visit Your Medical Professional, Office Staff and Emergency Personnel - Thank your medical professionals and emergency professionals for their care, and ask them to place the June Awareness Month posters up in their offices. Bring your local EMS/first responder station the Emergency Management 1 brochure for medical professionals, which can be found at the MGFA web site, www.myasthenia.org. Also ask doctors and medical staff if you can bring in brochures about MG and place them in their offices for newly-diagnosed patients, or existing patients who may need further information on MG.
3. Use the June Awareness Poster as a Talking Point - Bring June Awareness posters to public places, e.g. libraries, grocery stores, shops, pharmacies, senior centers, churches, etc., and ask if you can post the MG Awareness Poster in their facilities through the month of June. Ask schools and civic associations if you can give a talk on rare diseases such as MG; visit a senior Center in your town and talk about MG in older adults; ask your place of worship if MG Awareness Month can be announced during a service, or if information can be included in the weekly bulletin.
4. Join an MG Walk – In four years, the MG Walks have raised \$3 million and now are taking place in more than 30 cities across the nation. The MG Walk Campaign generates awareness, renews hope, and creates a community of support and strength across the country. The MG Walk enables patients to talk about their illness and experience an outpouring of support, concern and pledges from loved ones to do more. Consider joining an MG Walk in your city and raising vital funds for the tens of thousands Americans who live with MG every day. If there isn't an MG Walk location near you, sign up for the Virtual Walk. Visit www.mgwalk.org for more details.
5. Wear an MG Walk Shirt – Nothing translates awareness more than the attire people wear. When you go out, wear an MG Walk shirt, and if you get that confused look, tell people about Myasthenia Gravis – what is it? How can they help? Ask them if they would like a shirt, as well, to spread awareness in the local community. Encourage your support group and local patients and doctors to also wear MG Walk shirts.
6. Alert the Media - Contact local media about your local MG support group and its efforts; select a local patient who has an appealing story and make them the feature of a press release to try to garner attention in the newspapers or TV stations about what patients dealing with MG go through on a daily basis. Send a letter to the editor of a local newspaper. Invite individuals such as: newspaper editors and journalists, to your support group and events for MG Awareness month. If they can't attend, ask if you can submit an article and photo for publication.
7. Be a Social Media Bug – According to Pew Research Center, more than 50 percent of adults use more than one social media site a day, with 71 percent of online adults using Facebook, 28 percent using Pinterest, 26 percent using LinkedIn, 26 percent using Instagram, and 23 percent using Twitter. These social media sites have all made the social media world a very popular one for people to visit daily, so share your personal story on such a site and encourage others to do the same as well. Tell everyone you have MG, share your experiences with MG, and let them know what they can do to help raise awareness and research funds for MG.
8. Make/Ask for a Donation – Donations can be made at the MGFA web site at myasthenia.org or through the MG Walk web site at mgwalk.org. Both vehicles provide for means to raise MG awareness and funds for research to find a cure.
9. Hug Your Caregivers, Family and Friends - Hug your caregivers, family and friends, and remind them that they are special for taking care of you and supporting you through the many trials and tribulations and daily grind of living with MG.
10. Encourage Fellow MG Patients with Hope – Many MG patients and those with chronic illnesses struggle in their daily lives to continue to find hope and support to get through the day. Wish a fellow MG'er good health and encourage them to talk to you if they need to voice their frustration. Or, simply ask how are they doing? If there is a local patient with MG in the hospital, visit him or her. Comfort them and encourage them to never give up, and let them know that they are not alone in their fight. MG may bring them to low places and dark days, but fighting the disease and controlling the symptoms can bring forth character and resiliency and also give you the ability to reach out and help someone else find their way through their troubles. One way of doing this, if you haven't already, is by joining a local support group. A list of support groups can be found on the MGFA web site.

Cover article continued

MY JOURNEY AS A MYASTHENIA GRAVIS (MG) CARE GIVER



Dorothy & Herb Johnson

Our search for a diagnosis took a couple of months. We listened to our Neurologist explain this new found (to us) disease – MG. Although the Doctor had a treatment plan for this treatable but not curable disease, we were very worried and confused. It seemed the Doctor was medically treating her, but no one was helping us to learn “how to live with MG”! We searched and fortunately stumbled into the Triad MG Support Group (SG). Between the Doctor and SG over the years, we have a better understanding of how to live and treat Dorothy’s MG which is now under control. We have slowly adjusted our lifestyle and accepted our new “normal”. We were so grateful for the SG that we decided to “give back” to other MG patients. Dorothy is now facilitator of the Triad MG SG and I joined the Carolinas Chapter’s Board in the role of improving MG Awareness and Patient Advocacy, and later as Chairperson. Now let me tell you about my caregiver journey.

Prior to my retirement and Dorothy’s MG diagnosis, we had retirement plans to travel. Well, those plans quickly were put on hold and certainly had to be adjusted and downsized. With Dorothy’s new normal lifestyle we had to limit our traveling activities. The hardest part for me was to psychologically adjust to this part of my retirement plan.

The next thing I had to do was not only become my wife’s caretaker, but I had to become her medical MG partner. Prior to her diagnoses I had barely heard of MG and certainly did not know how to spell it or correctly pronounce it. Well, now I had to learn. I read educational materials supplied by MGFA

and our SG. We listened to other MG patients’ stories from our SG including successes and failures, which confirmed all the variability in the manifestation of this disease. This gave us a better understanding of why it is called the “snowflake” disease - because under a microscope, no two snowflakes have the same geometric design, which is how MG symptoms and treatments can vary from patient to patient! To continue my education as a medical MG partner, I searched the internet for information. I certainly found a lot of information and quickly learned that I had to be careful to use websites from credible sources so I would not be misinformed or misled. Another great education source, certainly of what was the latest research and development were the sessions at MGFA’s National Conferences, as well as talking with other MG patients, caregivers and medical professionals who were in attendance.

On a personal basis, we had to make many adjustments to our day to day lives because of Dorothy’s diagnosis. I am sure many people have had to make similar adjustments in their lives based on health issues, so we’re not unique.

I have observed that an MG patient must define and accept the new normal for their life. If done, it provides the necessary “balance” to live with MG – from both the physical and mental perspective.

My initial approach was to do everything I could to take any physical or mental burden off of Dorothy. I did such a good job that I frustrated her. Because I tried to do everything I could for her I did not realize that I was hurting her. My efforts were taking away her dignity because of how she had defined herself – a good partner doing her share of the duties which she could not do anymore because of her MG. It depressed her to see me do housework, cooking, grocery shopping, washing, etc. because those were some of the activities that defined her as person. In this case I was being too helpful. We had a heart to heart talk. After she got stronger, we agreed that she would try to do more tasks and ask me for help when she felt she could not do them. In my attempt to be so helpful to her, I had not seen that

I was taking away her dignity as a human being. This situation reinforced the fact that to have a good relationship, we must have good open communication on a continuing basis. I have observed that an MG patient must define and accept the new normal for their life. If done, it provides the necessary “balance” to live with MG – from both the physical and mental perspective.

By disposition I am a giving person so the role of caregiver came naturally to me. Therefore the activities we share together such as going to movies, playing cards with friends, limited traveling, etc. keep us mentally healthy. I personally have

found my work with the Carolinas Chapter of MGFA to be very fulfilling. The work can be exhausting and overwhelming at times, but the reward I get from being able to help another MG patient or caregiver find MG answers, medical understanding and camaraderie with someone in a similar situation has reenergized me.

I hope you have found my experiences and insight helpful in your caregiver journey!

Herb Johnson
Chairperson, Carolinas Chapter

MG STORY IDEAS WORTH WRITING ABOUT TO THE MEDIA

Below are some MG story ideas that may help you to garner some press attention. Some of these ideas are producible for MG Awareness Month June 2015; others may be more appropriate to pursue over a longer timeframe. Remember that June may be MG Awareness Month, but Awareness Is All Year Round! So, if you find an idea here or come up with your own idea that takes more time, pursue it!

- Give an award. Is there someone in your community who has made a significant contribution to MG, your chapter or support group, or to improving health? Consider honoring that person with an award. An award can be given at almost any significant gathering of people – at a club meeting for instance. Invite the local community paper. Take pictures and post them to your Facebook page. Brainstorm on how to make the most of this opportunity.
- Promote a human interest story. Do you know an MG patient who has triumphed against adversity? Interview that person, write up their story. Promote the story to community press, and/or post it on the web.
- Post Interviews with MG patients on the web. Work with your MG community members to identify those with family members, grandchildren, children, siblings and spouses, willing to interview their MG relation about their challenges and victories in coping with MG. Post the interviews to social media. Show them at a chapter or support group event. Invite local press and send a press release announcing the project and its achievement.
- Work with your schools. For instance, approach a science teacher or athletics coach at a local high school, to produce an event focused on MG. With the science teacher, suggest a class project around the science of MG. Students could research MG then participate in a quiz show event perhaps in the school auditorium where family and MG patients could attend. Local retailers could be approached for prizes. Or, pursue an event with an athletic focus ...
- Partner with a sorority or fraternity. Do you live in a college town? Consider partnering with a sorority or fraternity to produce an event focused on MG.
- Speak before local clubs or church groups. Work with your members to identify local clubs (Kiwanis, Elks, etc.) and groups that might be interested in a program about MG. Pick a few members who can speak

to an average person about MG, symptoms, treatments, why it occurs, the variability of how it shows itself in “snowflakes.” If members are concerned about public speaking, another approach might be to have two members, one the interviewer, the other the interviewee. Or, work with a local doctor and pair up a physician with a patient to talk about MG.

“Either write something worth reading or do something worth writing about.”

– Benjamin Franklin

- Work with local artists. You may find contacts through a school or nearby arts community. For instance, approach a college arts program about producing a show focused on the challenges of a chronic disease like MG. Have support group or chapter members make a presentation to students. Work together to produce a show in which the artists interpret their understanding of MG in their media, painting, poetry, sculpture, etc. Focus not only on the challenges but also learning to cope and finding joy despite MG.

AWARENESS IS ALL YEAR ROUND!

Team ENDurance MG: For those who want to go the Extra Mile!



The MGFA is thrilled to announce a new fundraising and awareness initiative... Team ENDurance MG!

Building on the success of the MG Walk, this new and exciting program will not only give the MG community the ability to raise funds for the MGFA and spread awareness about myasthenia gravis, but this campaign will enable MG constituents and their family & friends to train and accomplish a “bucket list” activity such as a half or full marathon, triathlon or biathlon or even an obstacle course race in mud!

Team ENDurance MG has several goals...

- Generate greater awareness about myasthenia gravis and continue to grow the MG constituent base
- Provide the MG community and their family and friends an additional opportunity to participate and raise funds for MG
- Allow those who are looking to participate in a challenging and gratifying endurance event, a chance to participate on behalf of MG and the MGFA

So why should you join the Team?
The real question is... why not? Team ENDurance MG is the perfect program to join if:

1. You are already participating in an endurance event (Full Marathon, Half Marathon, Triathlon, Mud, Color Run, Hike) and you want to raise money (and awareness) for the MGFA and myasthenia gravis.
2. You have always wanted to participate in an endurance event and now is your chance to check it off your bucket list...while raising funds for a cause close to your

heart! If so, you can view some options by going to <http://www.teamendmg.com> and choosing the Participate button above or contact the **Team ENDurance MG** office. We can then help you find a suitable event!

3. You have a family member or friend who would participate and raise \$\$ on behalf of MG.

The first Team ENDurance MG participant was our National MG Walk Director, Rich Mauch, who recently completed 13.1 miles in the NYC Half Marathon on behalf of the MGFA. In addition to Rich successfully reaching the finish line, he raised more than \$11,000 for **Team ENDurance MG!**

Do we have your interest or a family member's, a friend's or a colleague's interest?

Please visit www.TeamEndMG.com as well as contact the Team ENDurance MG Office at 855-649-2557 or Info@TeamENDMG.org if you have any questions regarding your...

- Preferred event or location
- Event registration fee
- Fundraising expectations
- Race attire
- Incentives
- Potential travel plans
- Other questions!



Join MGFA on
TWITTER
Visit
<https://twitter.com/MyastheniaOrg>

There is a list of many endurance events around the US and world on the website that are still open for registration. You don't see an event you would love to participate in, no worries ... let us know and we will help you find something of interest.

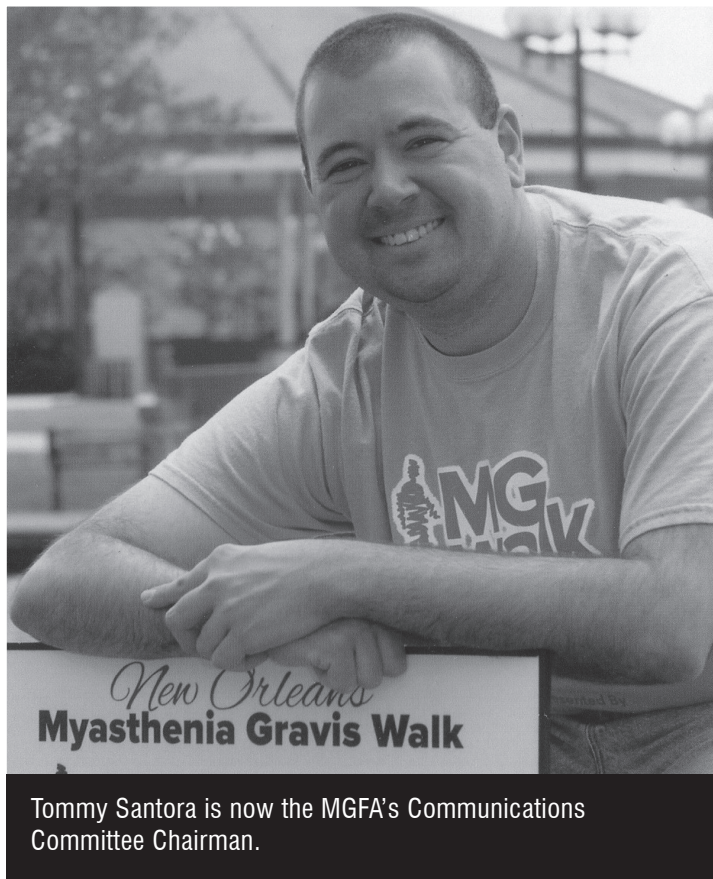
And you can follow Team ENDurance activity at [facebook.com/TeamENDuranceMG](https://www.facebook.com/TeamENDuranceMG)

We look forward to hearing from you and your family and friends as **Team ENDurance MG** will bring us even closer towards the ultimate goal and finish line...an END to MG!

Parenting a Child with MG – Three Stories of Love

Tommy Santora

by Linda Macke



Twenty four years ago it seemed I was always stressed about something, relationships, work, living month to month, and simply trying to survive as a single Mom! It was then however that my priorities changed. My son Tommy, who was 12 years old at that time, was already in his 8th year of playing sports, baseball, basketball, and football. He had just completed an awesome baseball season making the playoff game winning hit! Basketball season started and Tommy was somewhat challenged when running full court. I'm embarrassed to say that I actually fussed at him about his performance. Sadly we get caught up in living through each hectic day and we sometimes are not paying close enough attention to those who are nearest and dearest to us. I found this out the hard way. We foolishly take each day and those precious moments for granted and they can be taken away from us so quickly.

Tommy was undoubtedly suffering through playing basketball... dealing with his weakness quietly so as not to upset me. When

baseball started it didn't take long for the Coach and I to realize something was seriously wrong...Tommy barely made it around the bases during the first night of practice. Within days his leg weakness was progressing. He was having difficulty walking and struggled to even sit up in his bed. I remember sitting in his room while he was sleeping, looking at all of his trophies, sports posters and statues, video games, and plaques. I was thinking about the day I scolded him and his brother when they broke my bedroom lamp after I told them to be careful, or about the day I found all of his school papers with the bad grades under his bed.... all of the "little boy" stuff Moms freak out about and then laugh about to themselves

Our family found out early on that we could only sustain this battle by thriving off of Tommy's determination and inspiration.

later. I started to pray to God...to forgive me for questioning his basketball performance ... to please let me be sick instead of him ... to please give my son his life back ... I pleaded ... please do not take my precious son away from me ... I could not even bear the thought of living without either one of my wonderful sons ... they are the reason I exist. I felt so inadequate as a Mom ... how could I not be aware of the physical and emotional pain he was going through ... how did I not see it? I realized then just how terrified and devastated I was but also knew I needed to hide my fear from Tommy.

We would soon find ourselves rushing to Children's Hospital here in New Orleans. I could hear them frantically paging Dr. Ann Tilton, a neurologist. Tommy was so weak and frail. I could feel his eyes follow me around the room ... they were filled with both fear and hope. He looked at me for reassurance that I could fix this for him and make him better ... I could no longer protect my son the way he needed me to ... I felt helpless. There were so many frightening possibilities. Through the grace of God Dr. Tilton saved Tommy's life by quickly getting us an answer. She diagnosed Tommy with Myasthenia Gravis. No one in our family had ever experienced symptoms like this. We certainly had never heard of this disease and quite frankly it would be a while before we could even pronounce it. We found ourselves gathering up as much information as we could and ultimately found that we would be fiercely battling this horrific disease for the next 6 years. At that time we were told that it was rare for MG to attack someone his age...we now know that it does not discriminate by age, gender, or race.

Even though Tommy and I would have the enormous love and support of our entire family we faced our fate together ... we knew we had a battle on our hands ... that our lives would be forever changed. There would be countless transfusions, surgeries, many experimental dosages of medication ... and of course the constant fear that one or more of these drugs could have adverse effects on the rest of his system since he was so young. We spent many hours in the waiting room at Children's Hospital. It was there that we both realized there were so many other families fighting even bigger battles than us. We decided to face MG head on! I asked for God's guidance, spent hours in the Chapel, and prayed many Novenas to St. Jude. Tommy's motto over his bed was "Never Give Up"! Our family found out early on that we could only sustain this battle by thriving off of Tommy's determination and inspiration. We were told to hope for longer periods of remission ... to simply pray that one of the many treatments they tried would finally be the effective one. No one ever promised us that even if and when we won this battle against MG that it would ever really go away completely.

Thankfully Tommy has been in remission for a while now. MG has reared its ugly head on several occasions ... droopy eyelids and double vision would be added to his symptoms and even today he is still on a closely monitored amount of prednisone. He's constantly aware of the importance of exercise and a healthy diet. Tommy would go on to become an extremely talented journalist, sports writer, photographer, recognized as one of the New Orleans Healthcare Heroes, named in the Top 40 under 40, and honored as a local Millennial! He's been the Communications Specialist for Adams & Reese LLC for 8 years and tutors students for ACT and SAT tests. In his "spare" time he plays on several adult baseball teams! During football season you'll find him watching all of the Eagles Football games. Tommy's incredible wife Whitney shares his life and she's never too far from his side. I call her "Heaven Sent" for not only Tommy but for the entire family. I admit that I don't worry nearly as much about Tommy anymore 'cause I know...she's on it!!

Four years ago Tommy founded the New Orleans MG Support Group. It's a wonderful and supportive family that we are all now a part of...our meetings and social events are filled with lots of hugs! Tommy told me that this is his way of "giving back". He feels that it's very important to provide the members with all of the love, compassion, understanding, and support they need. They appreciate the fact that he can personally relate to how they are feeling. Tommy is currently on the National Board for MGFA. It gives him great satisfaction to bring back all of the latest updated MG news from the seminars to the members and their families as quickly as he can. He uses his organizational skills and communications expertise to get things done and

we are now proudly preparing for our 4th Annual MG Walk on April 11th. We have raised \$125k over the past 3 years and had approximately 350 people at our Walk last year with over 30 local Sponsors. Since MG is so often misdiagnosed we all feel that raising awareness is as important as fundraising.

Tommy deeply cares about others and takes on every single project with his whole heart and soul ... that's the way he played sports as a young boy and that's how he lives today. Unfortunately we are aware that MG will probably be a forever threat to our lives, however, for now, Tommy chooses to help others with their battle. It's been both a privilege and honor to be right by his side in this fight and truly a blessing to be his Mom!

Michael Mazzarelli

By Andrea Mazzarelli



Michael Mazzerelli and family

I was a 37-year-old mother of two children, ages two and four, a successful businesswoman and wife when I was finally blessed with a diagnosis of Myasthenia Gravis. I say "blessed" because it took "forever" over a year, which at the time, seemed endless, to figure out what was going on with me countless doctors'

appointments and all sorts of tests. I thought, "Great, I can take some medicine and be back to my normal self."

Well, it hasn't happened YET, even after 10 years. Between my symptoms getting worse with the double vision, problems holding my head up, weak arms, and the terrible fatigue, I had to leave my job. After two years, it was discovered that I had a thymoma. I had that removed, but none of my symptoms improved. I tried Rituxan and that also did not help. Then, on top of the other symptoms, I started having a lot of difficulty swallowing, walking up stairs, and walking long distances, which means I have to use my walker or wheelchair at times. I have had several hospital stays for crises, which are really scary. I have IVIG every four weeks, which is a two-day, eight-hour infusion. I still have daily problems with all my symptoms. I know stress plays a huge role, but at times, the stress is not under my control, just as it really is under no one's control. A fleeing move to another state, a divorce, and being a single mother of two with this disease is demanding. THANK GOD for my great family and great friends, for without them I don't know where my kids and I would be.

Two years ago my son Michael, who was 10 at the time, started complaining about seeing two things at once. I thought, "No, it can't be MG!" So, off to the different doctors' appointments and tests again! His diagnosis was indeed MG. As a parent, the initial reaction permeated my thoughts: "This CANNOT be happening; he's just a child who has already seen and been through way too much in his young life! Talk about unfair..."

The past two years have been problematic, to say the least. We take each day as it comes. Michael wears prisms for his double vision, which he HATES to wear. He deals with a lot of anxiety, from other issues and his MG. When he gets sick, his double vision gets worse which makes him tired. Michael's fears of having a thymectomy, getting worse like me over time and not being able to play his favorite sports makes me cry that he deals with such unknowns for him. I do everything I can to assure him that he will still be a "normal" kid. Thankfully, he is still able to play his favorite sports, baseball and basketball. He is a GREAT player at both! No matter how bad his vision or how exhausted he may be, he's there! He's a huge fan of the Angels, especially Mike Trout, so a baseball player is what he wants to be!! His ambition, for now, is to see an Angels game and get Mike Trout's autograph.

In June of 2012 Michael and my daughter Mikayla raised over \$2500 for NYC Tri-State MG walk. I'm so proud of them. We all had a great time at the walk. Being able to talk with others that have MG or not was a great experience as well as for them to see NYC!!!

We deal with all our STRESS, difficulties, emotions, bad days and challenges as best we can. When people feel bad for us, I say, "Please don't." As I have said since my diagnosis, "I/we could be much worse off, and I feel blessed for that." After all my kids and I have been through, I still feel the same way. We can never give in to this -- or any other challenges that come our way. We hope and pray EVERYDAY that some fabulous people find a cure for this unique disease.

Veronica "Ronnie" Adams

by Terri Adams



Terri Adams (on the left) with her mom, Betty Cabral, and her daughter, "Ronnie" Adams

Ronnie (Veronica Adams diagnosed with MG at the age of 23) is my inspiration, and in fact, she has always been my inspiration. As a child, she brought me countless moments of joy, excitement, and pride. Every parent knows how exciting it is to watch their youngsters score the winning soccer goal, hit a home run, post the fastest breast-stroke time, perform a perfect inward dive, and even make the National All-Star cheerleading squad. My Ronnie did all these things! My favorite pastime was to be on the sidelines cheering her on. I can honestly say that I never missed an event. She excelled not only at the myriad sports that she played but also in the classroom.

Ronnie graduated cum laude from American University in Washington, D.C. with a major in Justice and minors in Psychology and Spanish. After her graduation, she decided to stay in the D.C. area to start her professional career. Her career progressed quickly and she was living a happy and productive life. Today, even with her MG, Ronnie is completing her master's degree in IT Security at Georgetown University while working full time. Need I say more why she is my inspiration?

My hope for the future with regard to MG is two-fold. The first is to raise awareness of MG. When Ronnie was diagnosed with this wicked disease that attacks many young adults in the prime of their lives, our family looked at one another and said, "mya ... what?" (As I am sure was the case with other newly-diagnosed patients.) The words "Myasthenia Gravis" were hollow ones; they had no meaning to us at that time. I actually asked the doctor to please spell those hollow words as I wrote them down on a scrap piece of paper. Awareness is critical. Second, a cure needs to be found. Myasthenics need to know that there is hope and that a cure will allow this condition to go away so that they can resume their lives as normal healthy individuals.

Ronnie's MG journey was a lonely one. She experienced her MG symptoms while living and working in the Virginia/DC area. We dealt with her symptoms via the telephone. I can remember the first phone call, where she mentioned that her smile looked crooked. Immediately, we thought Lyme disease. Her dad and I sent her off to the general practitioner to be tested for Lyme. To our dismay, the Lyme results were negative – no Lyme!

You would think that one would be happy with this result, but we were not. The crooked smile continued and we did not know why. We asked her to come home to Connecticut to see an infectious disease specialist. This doctor was recommended to us by a friend who had Lyme disease. Our hope was that he could find the Lyme that the GP could not. Well, the verdict was still no Lyme. He told us to stop wishing for Lyme and that something else was going on and we needed to focus on that. Ronnie went back to VA disappointed and obviously worried. Our minds were wondering as we waited for the next GP visit. Could it be a bout of Bell's palsy, or could it be a stroke or a TIA (transient ischemic attack)?

Days went by when another worrisome call came in from Ronnie. This time she mentioned that she dropped a dinner plate, something that had never happened before. My immediate answer, was that she was stressed, working too hard, exercising too much (she was kick-boxing at that time), etcetera, etcetera. Every day I would call to see how she was doing and with each phone call another symptom seemed to appear. I can recall

her telling me that she fell while commuting to work – but can you guess what my response was to her? I told her that's what she gets for wearing high heels while commuting and walking the city streets of D.C. Never did we expect that these incidents of muscle weaknesses were from a rare autoimmune disease. I attributed these incidents to stress from the mystery of her crooked smile and work. Denial, denial, denial, or was it ignorance?

The next GP appointment finally came and the myriad of tests began. I went to Virginia for some of the more invasive tests, but for the most part she endured many of the required tests on her own. I would receive the nightly call where she mentioned that the GP thought maybe she had ALS, and then MS; then Sojourns, and then Lupus. A litany of autoimmune diseases was mentioned and ruled out one by one ... then came the final verdict. She went alone to her GP, expecting to hear that another autoimmune disease was ruled out and that another test was going to be recommended. Well, this time it was different. She heard those "hollow" words for the first time, "Myasthenia Gravis." What did Ronnie do? She cried in the doctor's arms and her mind blocked out everything that was said afterwards. As a parent, how would you feel knowing that she had to experience this alone? I will never forgive myself for not being there, but promised to never let this happen again. Next we started our neurological trek.

Her first visit was with a very nice, relatively young neurologist in Virginia. He immediately prescribed Mestinon. While we were discussing the disease with him, he made the mistake of mentioning that he had never treated a myasthenic and that we would all learn more about the disease together. I am sure his intentions were very good, but with our ignorance toward this disease, I could not let her stay with this doctor.

So I came home and I think I wore out the keys on my laptop searching for physicians that specialized in Myasthenia Gravis. I found a doctor at Mount Sinai Hospital in New York and called his office. He agreed to see her in the nick of time as her myasthenia was worsening, as slurring, difficulty swallowing and breathing symptoms appeared. After her first visit with this neurologist, he immediately admitted her to the hospital and she spent five days having a series of IVIG. She felt wonderful immediately after her first infusion. She was discharged with a prescription for a series of IVIG every four weeks. Ronnie stayed with us in Connecticut for a few weeks to recoup from her hospital visit and then it was back to Virginia and work.

Things seemed to be going better until her IVIG stopped and insurance caused her to find a doctor in the Virginia area, as the New York doctor was out of her insured area. Another MG crisis

occurred while we searched for a new doctor. She was taken by a friend to Georgetown Hospital where IVIG infusions were administered and where she was placed on 60 mg of prednisone to make her stronger. She left the hospital stronger, but soon the effects of a daily dose of 60 mg of prednisone reared its ugly head. Her Georgetown neurologist felt that the prednisone was necessary, but unfortunately, the prednisone did not like her. Her appearance -- and most significantly, her personality -- was transformed; she had become a different person.

So back to the laptop for me, searching for Myasthenia Gravis information and specialists for this wicked disease, as I like to call it. We learned about a Thymectomy and that she had a 33% percent chance of getting better with this procedure. While the percentage was not very high, we felt it was worth the risk and hence made the decision to go in that direction. She found a wonderful thoracic surgeon at Georgetown University, but was told that she could not operate on Ronnie until the daily 60 mg of prednisone was significantly reduced. Under the direction of her Georgetown neurologist, the prednisone weaning started. While we waited, it seemed that she was managing with the Mestinon, IVIG, and the reduced levels of prednisone. The day finally came for her Thymectomy. The procedure itself was a success and she was released from the hospital after one evening. I stayed in Virginia with her for the follow-up visits and until she was well enough to make the journey to Connecticut for her short-term rehab. She rehabbed nicely at our home. It was my pleasure to have her home.

But the time came for her to go back to Virginia to continue with her life. Things seemed to be going well when another setback occurred. Her insurance decided that the IVIG was no longer necessary and that her neurologist should put her back on the higher levels of prednisone. I think that those insurance gurus who prescribed this treatment should be put on high levels of prednisone and see what it does to their lives.

In the meantime, I was able to make contact with Dr. Gil Wolfe, a neuromuscular specialist, and explained our insurance woes to him. He graciously referred us to Dr. Henry Kaminski at George Washington University, who took Ronnie on as a patient. He was able to get her back on a series of IVIG and promised not to raise her prednisone level, a regimen with which she was very happy. Recently, her job caused her to move to New York City, where she is now under the medical care of Dr. Richard Nowak from Yale University. We chose him because Yale was close to Ronnie's home in New York City and our home in Connecticut. We found Dr. Nowak through the Connecticut MGFA Chapter.

Currently, Ronnie is in a medical remission requiring her

regularly-scheduled IVIG and, as Dr. Nowak calls it, her "psychological" 5 mg of prednisone. I cannot explain how happy we are right now. While I miss sitting on the sidelines of her sporting events, I now sit on the sidelines of her IVIG at the infusion centers. I enjoy being there with her because I know that this procedure is helping Ronnie live her life to its fullest.

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“A world without Myasthenia Gravis”

MG Walk Campaign: Celebrating 5 Years!



Now celebrating its' fifth year, the National MG Walk Campaign continues to work towards the ultimate finish line... a World Without MG. Hoping to build on the record-breaking results of 2014, this year's MG Walk Campaign has already seen 9 successful Walks with about 25 more to go...and is ahead of last year's pace with more than \$250,000 raised as of late April.

Whether you have walked every year, or this will be your first year, there is no better time to register than right now. Visit www.MGWalk.org to find your closest MG Walk, register, and begin fundraising. Or if there is not an MG Walk in your backyard, become a virtual walker. We need you to help the MG Walk Campaign reach new heights and take us even closer to a world without myasthenia gravis!

If you have any questions, need help registering, or would like more information, please don't hesitate to contact the MG Walk office at 1-855-MGWalks(649-2557) or Info@MGWalk.org. And please follow the MG Walk Campaign at [Facebook.com/MGWalks](https://www.facebook.com/MGWalks), [Twitter.com/MG_Walk](https://twitter.com/MG_Walk), and [Instagram.com/MG_Walk](https://www.instagram.com/MG_Walk).

For those that have already walked and raised vital funds... thank you! To the rest of the MG community, we look forward to seeing you at an upcoming MG Walk in 2015!







SMILE FOR MGFA

Did you know you could donate to the Myasthenia Gravis Foundation of America while shopping on Amazon? It's simple to set-up on an existing account or by creating a new one. You can shop as you normally do, there's no change in cost or convenience to you. Tens of thousands of products are covered. Go to <http://smile.amazon.com/about> to learn more and make MGFA your charity!

TID BITS

Myrtle Beach MG'er Brings Attention to Rare Disease Day, February 28, 2015

Beverly Watrous, a Myrtle Beach, FL resident and Support Group member was highlighted by WBTW News 13 on their website with her MG story. Check it out at <http://www.wbtw.com/story/28233238/myrtle-beach-woman-living-with-myasthenia-gravis-shares-story-to-bring-awareness>

Inspiration

Jane Eickholt, Support Group Facilitator for Central Ohio

After watching the wonderful movie *The Theory of Everything*, I wanted to know more about Stephen Hawking, his disability and how he has managed to live so long and well! I picked up a copy of My Brief History by Stephen Hawking and enjoyed reading about his life, his success and his positive attitude about his ALS. There are many photos starting from his childhood to present day and he discussed some of his challenges, as well as some of his brilliant scientific theories. As a patient with MG, I could relate to some of his muscle weakness issues, and his problems with choking, as well as relationship issues. You don't have to understand cosmology to benefit from this book!

Bhupendra O. Khatri, MD is the author of *Healing the Soul—Unexpected Stories of Courage, Hope and the Power of Mind*. Dr. Khatri is the Director of the Regional MS Center/Center for Neurological Disorders, Wheaton Franciscan Healthcare, Milwaukee, WI. Dr. Khatri has brought together the stories of patients, of hope, love, and healing in a book that also explores medicine and science, the healthcare environment and its issues as well as how intangibles such as stress, positive thinking, touch and caregivers can impact health. Dr. Khatri's book is available through Henschel Haus Publishing, Inc. at www.henschelHAUSbooks.com.

**Busque MG Español
Idioma Folletos**
– Próximamente –



**Look for MG Spanish
Language Brochures**
– Coming Soon–



Check
www.myasthenia.org
after July 1

News from the Field Support Group Reports

Manassas, VA MG Support Group

It goes without saying that we have all been through quite a winter with record snow falls and cold temperatures. As we celebrate the coming of spring and renewal of life, I am reminded of how important support groups are for those diagnosed with MG. When you first get diagnosed you are afraid, confused, angry, scared, in denial, and experience a whole gamut of emotions. Often times things get worse before they get better. But if you are fortunate enough to find a support group and strong enough to attend one, it can be like spring, like an awakening of a new life. But this time, a life with MG. Even with MG you can have a full and purposeful life. It will just be different. You will find a strength you never knew you had, and knowledge of synapses and neurotransmitters, and muscles that you didn't perhaps think you were capable of understanding. But through your own transformation and journey of living with MG, you will undoubtedly help others. You will stand together for a greater purpose and by helping others, you will help yourself.

As one member of the support group stated "The collective wisdom of the group has been a powerful treatment for me. It has been a wonderful support to know that I am not alone in this fight. The group....in many ways has been the best medicine for me."

To all those in the Manassas VA support group, I thank you for the time you take to attend the meetings, the help and encouragement you give to each other, and your efforts to increase awareness of this disease so that one day there may be a cure. That is our purpose.

Anita Steele
agsteele@hughes.net

Oklahoma Support Groups

The Oklahoma Chapter Support Groups take place in Tulsa and Oklahoma City. The Tulsa Group recently held, March 8th, a program on "Robotic Thymectomy" with Abbas Abbas, MD. They are also planning a Chapter Picnic in the Park, to be held June 7th in Tulsa's Lafortune Park, 61st & Yale, where we will celebrate "June as MG Awareness Month." Hot dogs, hamburgers, beverages will be provided. Participants are asked to please bring a picnic type dish to share. No RSVP is necessary.

Peggy Foust
oklahoma@myasthenia.org

New York City Area Support Group

The major event for 2014 was the attendance of the MGFA Fellowship awardee Dr. Ricardo Roda and his team. He is now at NYU working on his ongoing LRP4 research study. He got a terrific response for volunteers for the study. He is particularly looking for patients who are double zero-negative. As usual, the group has a full monthly schedule of meetings for 2015.

Sue Klinger
sueklinger150@gmail.com

Ames, IA Support Group

The Ames, IA Support Group has stopped having face to face meetings due to the difficulty of traveling and the spread out nature of the membership. However, we do have a private Facebook page and members email things back and forth to each other as needed.

Amy Schindel
amy.schindel@gmail.com

Minnesota Twin Cities Support Group

The Minnesota Twin Cities Support Group has been meeting since the 1970's. Initially as informal gatherings, the late '70's saw formalized monthly meetings in various locations, enjoying lunch, discussion, and programs. The meetings are held on the third Saturday of the month at 12:00 noon. (Except in September when we have our Annual State Meeting.) They are currently at Midland Hills Country Club, at 2001 Flam St. in Roseville (St. Paul). This is a lovely handicapped facility that has some convenient handicapped parking and space on a lower level. A delicious lunch is provided for \$14.00, which includes entree, accompaniments, dessert, coffee or tea, tax and gratuity. Lunch need not be ordered, if not desired. The group averages 23 participants, with a high participation of 35. They come from the Twin Cities and greater metro, the adjacent north and west, and western Wisconsin.

Lianne Anderson has served as chair. Dianne Tower, Laurel Meyer and Jane Armbrust currently assist with monthly reminder calls. In addition to contacting patients regarding programs and attendance, they serve as an interested contact and friend. All in the Twin Cities are invited to attend, even if they have not been called. The group enjoys a format of having programs, directed/ formal discussion, or sometimes sharing conversation, ideas and info with patients and families. The group also likes programs that go beyond medical to broader life issues. Some of the most popular past and recent programs have included qualified presenters speaking on: How to Prepare For and Have a Successful Clinic Visit or Appointment, Dealing With a Chronic Disease, Info

on diet and nutrition "What's On Your Plate", Tai Chi, Causes and Treatment of Dizziness, the MN Ombudsman's Office on Advocacy for Mental Health, Dev. Disabilities, and Invisible Illnesses, The Difference Between Weakness and Fatigue, Personal Safety, Fraud & Identity Theft - Roseville PD, & Easy Entertaining with MG. Our holiday gathering is joyful and includes music, singing, a gift exchange, and special guests including national and local Walgreens reps.

Upcoming meetings will include: Silver Sneakers (gentle) Yoga, Pharmaceutical Information and Questions, The Science Behind MG Symptoms & Medications, How To Work With Your Primary Care Provider, & Holistic Treatment of MG.

In our last survey, participants indicated the support group helped them by meeting and sharing with others, and getting info on MG and other topics. They said, "There is fellowship and understanding.", "Support and friendship alleviates fear.", "There is honest sharing with those who understand that you are not just "fine". It is a warm, welcoming and supportive group that not only gains information but strength from being together.

Lianne Anderson
liannema@mac.com

The Dallas/Fort Worth Support Group

During December we had a wonderful holiday get together with about 17 people coming to our home with the Chapter providing a delicious Honey Baked Ham and everyone bringing a dish. We also did a white elephant which was a lot of fun!

We are planning to have several speakers this year. Initially, we've talked about asking a Nutritionist to come and speak as well as a specialist on plasmapheresis

as these are two topics that many of our attendees are interested in.

The Dallas/Fort Worth Support Group is still meeting the second Saturday of each month 11:00-1:00p.m (different locations). Contact information: karon.faight@yahoo.com 972-489-5662

Karon Faight
karon.faight@yahoo.com

Michigan Support Groups

With multiple support groups in Michigan and vicinity there's lots of activity including presentations from experts such as a recent program on sleep as well as MG experts such as Dr. Melanie Taylor, Director of our Neuromuscular Program at Mercy Health scheduled for July 13th, Monday at 6:30 pm in Grand Rapids. Michigan is also looking for monthly or every other month leaders or co-leaders for support meetings across the state.

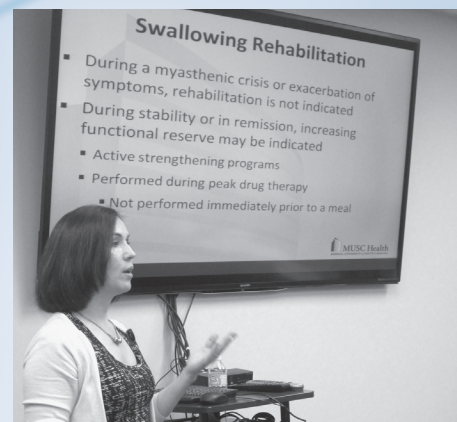
myasthenia.info@gmail.com

Low Country, South Carolina MG Support Group

Our support group is now in its 5th year. Until Julian Carnes and Janet Myder formed the group there was no MGFA support group in SC. A second one was formed 2 years ago. We continue to look for ways to reach more people who are affected by MG, and we look forward to continuing to serve the MG community and engage informative speakers.

After a low-keyed autumn 2014, we've had a very active first quarter of 2015.

Neurologist Dr. Katherine Ruzhansky who recently joined the Medical University of South Carolina (MUSC) was our first speaker. In addition to caring for the majority of MUSC's MG patients, she is



Ashli O'Rourke, MD, Medical University of South Carolina (MUSC) presents to the LOW COUNTRY SOUTH CAROLINA MG SUPPORT GROUP. She co-authored MGFA's very popular educational brochure on the subject with MUSC speech pathologist Kendrea Focht, PhD. Dr. O'Rourke's informative presentation addressed anatomy and physiology, effects of MG, common treatments, and prognosis and recovery.

Assistant Professor of Neurology and Director of MUSC's Neuromuscular Medicine EMG lab and is developing an Autonomic Nervous System testing laboratory. She gave a very informative presentation about current treatments for MG and clinical trials. We were very impressed and encouraged by her interest in and enthusiasm for our support group and especially her commitment to informing her patients about the group.

The effect of MG on speech, voice and swallowing was the focus of our February speaker, MUSC otolaryngologist Dr. Ashli O'Rourke. She co-authored MGFA's very popular educational brochure on the subject with MUSC speech pathologist Kendrea Focht, PhD. Dr. O'Rourke's informative presentation addressed anatomy and physiology, effects of MG, common treatments, and prognosis and recovery.

In February we also discussed ways

to spread the word about MG on Rare Disease Day, February 28th. The group posed for a photo with everyone holding the Rare Disease Day logo. The photo was posted on the official Rare Disease Day web site, on MGFA's site, and the support group's Facebook page and other social media.

Future topics for our group are pharmacy issues in neurocritical care, "my aching feet," and end of life concerns.

The group is participating in virtual walks for the first MGFA MG Walk in SC on March 28. In April we look forward to hosting board members of the Carolinas Chapter and guests from MGFA's national office. We view this as an opportunity to share our experiences and learn about MGFA's plans.

Julian Carnes or Janet Myder
mgsupport11@comcast.net

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St. Anthony's Support Group in St. Petersburg, FL

The support group and leader Jessica Simmerman are fairly new and still getting their group off the ground. Jessica reports, "Nothing really exciting with our group in recent months. I've been getting adjusted in this new role but feel this coming year will have good things happening. Hopefully I'll have more exciting details for you next year."

The group did start a refreshment committee...which rotates who is bringing the evening treats. We now recognize members' birthdays on a monthly basis by giving a signed group card. If they are not present I will mail it to them. We also do "get well wishes" and sympathy cards if there has been a significant loss. If we have a member in the hospital, there are a few of us that are willing to go visit if it's ok with the group member.

We are working on a "Welcome Kit" to new members. In theory this Kit will contain a general welcome letter, MGFA information i.e.: website address, Patient Registry, mg information, MGFA brochures, etc., journal to log medications and responses (important for recently diagnosed), and helpful tips and tools on doing ADL's. There are a few more things we have talked about adding to the kit but are still in the idea phase.

One of our members teaches yoga and we are hoping to offer free classes periodically for the members who are interested. The yoga would be modified to accommodate the needs of those with MG ... it would also focus on techniques to reduce stress and/or anxiety.

Jessica Simmerman
jesvair@gmail.com

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Greater Houston Support Group

"We held a wonderful holiday pot-luck at our December meeting, and enjoyed a room full of fellowship with family and



Members of the Houston Support Group

friends. We invited 2 speakers to share their MG story, and how support groups have impacted their journeys. Pat and Betty spoke, from the myasthenic and caregiver perspectives, respectively. In January, we celebrated our 1st anniversary, and talked about goals for the new year, and advice we have for new MG families.

The Greater Houston MG Support Group is growing at a steady pace and averages 25-30 members each meeting.

Rachel Higgins
rachelhasmg@gmail.com

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Pacific Northwest Chapter Support Groups

The Pacific Northwest has been very busy developing support groups throughout the area. They've got a lively series of programs. For instance, for the Seattle Area Support Group the theme for the spring 2015 meetings is "Come and Meet the Doctors." Upcoming meetings include:

- On April 19 - Dr. Steven Hamilton, Medical Advisor to the Chapter, and a board certified neurologist who has completed advanced medical training in the specialized field of neuro-ophthalmology will conduct a live "Ask the Doctor" session at the Fairwood Library in Renton, WA.
- On May 24 - Dr. Michael Weiss, Director of the Neuromuscular Diseases Division, is a UW Professor of Neurology and Adjunct Professor in the Department of Rehabilitation Medicine. He sees patients at the University of Washington Medical Center. Dr. Weiss will discuss "Emerging Therapies in MG" at the Mercer Island Library, Mercer Island, WA.

There are also support groups in the Spokane Area, Kitsap and the South Sound, as well as a new group for the Portland, Oregon Area and Coeur d'Alene, Idaho. We hope to have an additional support group in Southern Oregon later this year.

Kathie Bibeau
nwmg2012@gmail.com

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Hattiesburg, Mississippi Support Group

The support group held their annual Mr. Bill's Christmas Social. Everyone got dressed up in their holiday best and brought a dish to share. It was a lovely party with lots of good fellowship. A speech pathologist and an occupational therapist presented at meetings in recent months. I hope to bring the speech pathologist back sometime soon since it's such an important topic for those with MG.

Betty Ward

jward511@comcast.net

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Triad Area Support Group

The Triad support group tries to have speakers as often as we can. At our November meeting we had the privilege of having Tracey Brinkley a community activist who has overcome many challenges & has also received the

outstanding citizen award from the chamber of commerce in Thomasville. She is on the YMCA board of directors and is active in her church. She speaks with a very uplifting message, when she is asked. She is legally blind and has Myasthenia Gravis. The treatment she uses for her MG is to have plasmapheresis 3 times a week. Through many obstacles of depending on someone for rides to her treatments, church or other speaking engagements she depends on friends & feels blessed to have so many willing helpers. She spoke of her challenges & blessings with having MG. Her uplifting message was to make us all aware of the many blessings we have & that our strengths can overcome the problems we encounter in our daily routines. Tracey brought along a wonderful guitar player who sang a beautiful song for us which he does often at the infusion center for plasmapheresis.

Our next guest was a nurse (Gretchen) from the plasmapheresis infusion at Forsyth Hospital. We were privileged to have the actual machine they use for plasmapheresis and she explained how the blood is filtered through many tubes. She also explained the machine is used to take out the cholesterol in the blood. Another use is for dialysis when the kidneys aren't functioning properly.

We are looking forward on March 28th to have an MG Walk & hope to raise some money for research & awareness of MG.

The Triad Support Group continues to have a strong attendance, often with new members, coming together and sharing our MG stories with each other. We are thankful that we can help others better understand MG & support each other via the support group.

Dorothy Johnson

Nirvana@triad.rr.com

Update on Immunoglobulin Nurses Society (IgNS) 2014 3rd National Conference

By Ruthann Devine, RN, IgCN, Walgreens Infusion Services

Las Vegas was the location for the 3rd Immunoglobulin Nurses Society (IgNS) National Conference. The setting was ideal as it appropriately ramped up the enthusiasm of the participants. This year was particularly exciting as many nurses had pursued Ig Certification for the first time, while others were present to learn and prepare for upcoming Immunoglobulin Certified Nurse (IgCN) professional credentialing exams.

Individuals from competing organizations united with the common goal of collaboration in order to improve Ig knowledge and standardize best practices. A faculty of expert speakers freely contributed and shared best practices. They included Patient Advocates, RNs, NPs, Physicians, and Pharmacists.

The agenda was packed, and in just three days an amazing amount of information was imparted. Topics included advocacy and available educational and reimbursement resources for patients receiving immunoglobulin (Ig). Subcutaneous Immunoglobulin was presented

both for Primary Immune Deficiency and its use in neuromuscular diseases. MG Nurses Advisory Board members Wilma Koopman, RN, NP, and Vilija Rasutis, RN presented "Intravenous Immunoglobulin (IVIG) and Subcutaneous Immunoglobulin (SCIG) in Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), Multifocal Motor Neuropathy (MMN), and Myasthenia Gravis (MG)". However, it was noted that no data has been published with the use of SCIG and MG and further trials are needed.

IG manufacturers provided the latest developments with their respective products. Baxter Healthcare presented HyQvia (IgHy), recently approved monthly SCIG facilitated with Recombinant Human Hyaluronidase in a single subcutaneous infusion site. This product is indicated for adults with Primary Immune Deficiency and allows for infusion volumes up to 600 mls per site. Octapharma's newly approved Octagam 10% was presented and has an indication for treating Idiopathic Thrombocytopenic Purpura (ITP). CSL Behring presented Biweekly Hizentra SQ which allows for dosing flexibility for Primary Immune Deficient patients.

Disease state management was also a focus. Hematological indications for the use of Ig were presented with a wonderful overview of ITP, IVIG and SCIG and their many uses in both solid organ and Bone Marrow transplant were an additional plenary session.

Finally, as the professionals at IgNS continue to raise the bar, soon the development of Ig Standards of Practice will be used nationwide to ensure safe and appropriate Ig practices in the future.

The Nurses Advisory Board is offering a continuing education program and dinner for nurses and other interested healthcare professionals on Wednesday, April 29, 2015 at the 2015 MGFA Annual National Conference. The presentation is entitled "Polishing

Your Advocacy Skills" by Anne M. Williams, PhD, RN. This educational event will increase your knowledge and awareness of the role of nurses to serve as advocates for myasthenics and their family members. Specific strategies will be discussed to enable you to become more effective as patient and family advocates.

This activity has been submitted to the American Association of Neuroscience Nurses for approval to award contact hours. The American Association of Neuroscience Nurses is accredited as an approver of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

Program Registration: Contact Martha Jones at mgfa@myasthenia.org or call (800) 541-5454.

Chapter's Corner

Nutmeg Chapter, Connecticut

We had our first board meeting in January and established our calendar of events for this year. However, with the frequent and heavy snowstorms in our area, we have not scheduled any events until April. We did host our annual chapter meeting in Oct 2014 with special guest Bridget Noujaim. Some excerpts from *The Nutmeg*, the Connecticut Chapter newsletter:

"Keynote Speaker Bridget Marie Noujaim (MG patient and former Board member) took to the podium for a poignant and emotional presentation about her personal life with MG. The audience was exceptionally attentive listening to Bridget's struggles with MG and how it changed her life and forced her to adjust to this malady. ...

She shared her thoughts on things that she learned about life and living with MG. Here are a few:

"I've learned that I like simple. Simple can be awesome. Who knew?"

"I've learned that 'hope' can be a dirty,

four-letter word. And optimism can be highly overrated."

"I've learned it's not true that God won't give you anything you can't handle. But somehow, God will give you the strength to handle whatever you get."

Anna Denninger, Chapter Chair
anna.denninger@gmail.com

Carolinas Chapter

Carolinas has been busy planning 2 MG Walks which will have taken place by the time you see this newsletter:

- Saturday, March 28, 2015 in Raleigh, NC at Lake Lynn Park.
- Saturday, March 28, 2015 in Columbia, SC at Riverfront Park and Canal.

Carolinas is also in process of establishing a new Support Group in the Columbia SC area and should be up with a meeting during the 2nd half of this year.

Herb Johnson, Chairperson
hmj@triad.rr.com

Arizona Chapter

The Arizona Chapter had their annual meeting, electing Jim LoVecchio as chair, Stephan Borski 1st vice chair, Ron Luna 2nd vice chair, Meg Clark as treasurer, and Anna Lopez as secretary.

The Chapter is sad to announce the passing of long time board member and Past Chairman Edward C. Kaps, III. He was a member of the board from the early 80's and served in many different positions, most notably as chair for more than 10 years. As he would proudly proclaim he "was almost 90 years old".

Jim LoVecchio, Chairman
lovecchio@dakotacom.net

Upstate New York Chapter

Our long time former chapter vice chair, Nancy Lenahan, lost her life due to injuries she received in an auto accident in Florida a few weeks ago. Nancy was loved and revered by all who had the good fortune to know her.

Barry Levine
blevinemgfa@verizon.net

What's Hot off the Press in Neuromuscular Junction Disorders?

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We hope you enjoyed the last edition of this column. In this issue, we will discuss studies that have looked at some of the risks of steroid treatment in myasthenia gravis (MG), the development of MG after removal of the thymus, work on a “vaccine” for MG, and recent work in Lambert-Eaton myasthenic syndrome (LEMS).

Corticosteroids such as prednisone are often used in the treatment of MG as they are effective and have a relatively fast onset of action compared to other medications commonly used to treat the disorder.¹ There are many potential long-term risks associated with prolonged corticosteroid use, including the development of diabetes mellitus. A previous study reported an absence of increased risk for MG patients of developing diabetes.² Yeh and colleagues³ recently re-evaluated this question in a large study of Taiwanese MG patients. In this study, the investigators used data from 1,520 patients with MG and 6,080 similarly-aged healthy patients. Corticosteroids were used in 51% of patients with MG. After adjusting for age, gender, and other measures, the group with MG had a 1.26-fold increased risk of developing diabetes compared to the group without MG. On further analysis, the investigators determined that the increased risk of developing diabetes was only higher for MG patients treated with corticosteroids. The risk was greatest for those receiving higher doses of steroids. Other identified risk factors included a history of thyroid disease, the use of prior “intensive” therapies to treat MG (for example, plasmapheresis, thymectomy, or need for mechanical ventilation to help breathe during crisis), and male gender. Limitations of this study include the lack of controlling for other risk factors that predispose to diabetes including body mass index, physical activity, socioeconomic status, and family history. The authors point out that their large sample size, use of a control group, and complete dosing records are key differences between their study and prior investigations that did not demonstrate an association between steroid use and the development of diabetes in patients with MG. This study highlights the need to monitor patients with MG who are placed on corticosteroids for the development of diabetes.

Thymoma, a tumor of the thymus gland, occurs in roughly 10% of patients with MG and conversely 15% of patients with thymoma have MG.^{4,5} An often observed phenomenon is the development of MG in patients after undergoing thymectomy (removal of the thymus) who had not previously experienced symptoms suggestive of MG. Yamada and colleagues⁶ aimed to identify the risk factors in the development of post-thymectomy MG in a group of patients who had undergone thymectomy for thymoma. Of the 239 patients in their study, 123 (53.7%) had no history of MG prior to removal of the thymus. Of these 123 patients, 10 (8.1%) developed MG after surgery with a range of 3 to 2,859 days following the procedure. The authors determined that having acetylcholine receptor antibodies (AChRAB) in the bloodstream before surgery was closely related to ultimately developing MG. They also found that certain types of thymoma and incomplete removal of thymoma were other risk factors. The authors conclude that AChRAB levels should be checked in patients with thymoma prior to surgery, and patients found to be positive should be followed carefully after surgery for the development of symptoms consistent with MG. Furthermore, they reiterate the importance of a complete removal of the thymus in order to

Make A Difference For MG

Participate in the

 **MG Patient Registry**

Go to mgregistry.coph.uab.edu/MGRegistry/SignUP.aspx

The MG Patient Registry is designed to help build data on the real world of MG -- real patients, real information. To participate, plan to gather your medical records, such as prescriptions, and set aside some time to enter your information. Your investment of time will make a major difference in our knowledge base and ability to conduct meaningful MG research.

ensure not only freedom from malignancy but also to reduce the likelihood of ultimately developing MG.

Development of a vaccine to “cure” MG has been on the minds of patients and investigators for many years. Vaccines that would target the AChR could potentially lead to the body’s immune system attacking it and causing MG, rather than preventing the disease from occurring. Lindstrom and colleagues⁷ have been exploring the use of portions of the AChR as a basis for a vaccine for some time. Their most recent study using rats demonstrates that the strategy of using certain portions of the AChR is safe, does not induce MG in the rats, and is more effective in preventing onset of chronic forms of MG if delivered in repeated doses every one to two weeks.⁸ Of greater importance, established MG in the rat models was rapidly reversed, reflecting how a vaccine would potentially be used in treating human subjects. Furthermore, successfully treated rats demonstrated long-term resistance to re-induction of MG, suggesting that they were cured from developing a clinical autoimmune response as is seen in MG. Although a favorable effect was not universal in the animals, this study appears to be an important step forward in what has been considered a holy grail of therapeutics for MG in humans.

For more on this vaccine study, see Dr. Lindstrom’s answers to Foundation Focus’s questions on page 24.

Moving to Lambert-Eaton myasthenic syndrome (LEMS), the group in Oxford, England has demonstrated direct evidence that antibodies from patients with this disorder reduce the release of chemicals at the neuromuscular junction (NMJ) by their effects on what are called P/Q type voltage gated calcium channels (VGCC).⁹ These antibodies are very often found to be present in the bloodstream of patients with this disease. In this study, antibodies from patients with LEMS reduced the rate of chemical release at the NMJ in normal samples, demonstrating their disease-causing effects. Although this mechanism has long been suspected in LEMS, the available evidence until this time has been indirect largely based on electrophysiologic measurements. This is an important study which confirms the role of these antibodies in the development of LEMS.

Thanks again for reading about recent research in the field of NMJ disorders and we look forward to keeping you informed in the next issue!

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A Sad State of Affairs

By Henry J. Kaminski, MD
Former Chairman of the
MGFA's M/SAB, Member
MGFA Board of Directors,
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The National Institutes of Health is the single largest funder of biomedical research in the world with an FY2014 budget slightly higher than 30 billion dollars. This US government agency is charged with supporting “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.” From about 2003, this mission of the NIH has not been a point of interest for our nation’s leaders, be it the Congress or the President. See the chart accompanying this article for a visual analysis of the agency’s funding since 1995. This may seem surprising. After all every few weeks in the lay press we hear about stunning advances in medicine and new government programs like the BRAIN initiative, which will “map” the human brain’s connections. However, one needs to appreciate that new treatments that are built on fundamental understanding of human biology, are hard to come by. For instance, nearly a thousand drugs thought to be effective in animal models of Alzheimer’s disease have failed in human clinical trials. The difficulty in producing drugs for neurological conditions is so high that pharmaceutical companies have retreated from this type of drug development. So where does this leave myasthenia gravis?

One can search NIH research grants by disease at <http://report.nih.gov/>. As of February 2015, one generates a list of 39 grants. That seems very good, until one looks carefully and appreciates that only 3 grants are specifically studying MG. Others are for conditions somewhat related to MG or, most commonly, investigations of autoimmune disease in general and may, or may not, lead to better understanding of MG. The Grants are: 1) Thymectomy in non-Thymomatous MG Patients on Prednisone, Principal Investigator: Dr. Gary Cutter, University of Alabama at Birmingham, the MGTX clinical trial rigorously evaluates the role of thymectomy in treatment of MG (full disclosure--Dr. Kaminski is part of the executive committee of this trial) and will be completed this

year. 2) Immunological Biomarker Studies in Myasthenia Gravis, is a career development award to Jeffery Guptill, MD, Duke University Medical Center, to continue his advancement as an investigator dedicated to MG. 3) A Phase II Trial of Rituximab in MG, Principal Investigator: Dr. Richard Nowak, Yale University, assesses safety and efficacy. Each of these investigators is a member of the MGFA Medical/Scientific Advisory Board. The MGFA has provided support for aspects of the “MGTX” trial and Dr. Guptill received funding from the MGFA to start his research career. So there you have it, 3 programs for MG totaling less than 1 million dollars per year of support or 0.003 percent of the yearly NIH budget.

Figure 1: Current and constant dollar funding for NIH

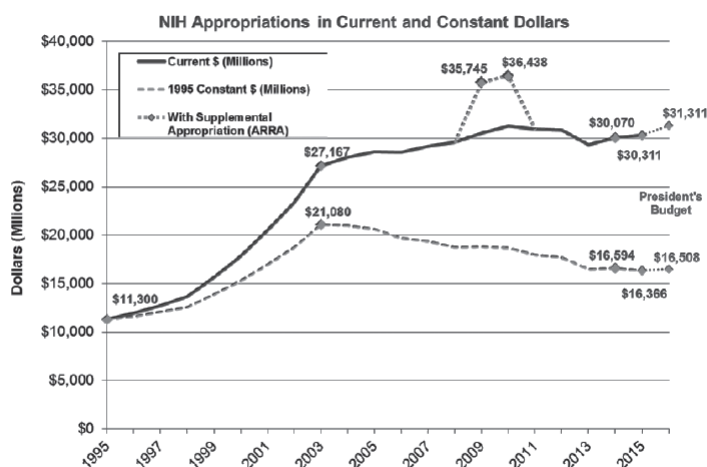


Figure 2: Number of competing RPGs and R01-equivalent awards

Please appreciate we are not advocating for competition among rare diseases, in fact the MGFA, is a member of a critically important organization that promotes collaboration with other rare disease organizations (NORD). What we do recommend is you actively participate in our democracy as an advocate for increased research funding to improve diagnostic tools, increase treatment options and improve understanding of the causes of MG. Write (letters or email) your national and local representatives to support increases for research. Please see the sample letter accompanying this article as an example. Participate in MG Walks and local events for MG Awareness including June MG Awareness Month to educate the public about the short fall in research for orphan diseases such as MG. If we are to improve the lives of those with MG and ultimately find a cure we need each of you to get involved in bringing attention to this problem.

Write Your Representative

SAMPLE LETTER Keep your letter to one page.

Date

The Honorable – Title Name—

Address

RE: Bill Name and # or Your Topic

Dear [Senator, Representative, State Senator or Assembly (wo)man or other title]:

What if you couldn't hold a pen in your hand? Smile? Breathe? What if you had Myasthenia Gravis (MG)? Today, over 70,000 people in the U.S. suffer from MG, a debilitating chronic auto-immune neuromuscular disorder that is characterized by fluctuating weakness and fatigue in the voluntary muscles. Eyes, facial muscles, limbs, swallowing, breathing are among the essential functions of the body that are affected. Although there are treatments, there is no cure and the treatments leave much to be desired in terms of results and their side effects for the patient.

I urge you to support funding for research into rare diseases such as MG. [If you are writing in relation to specific legislation, name the bill and # and address why you feel it's important.] Now more than ever, we are in a position to make a difference through expanded research funding. With so many discoveries and new opportunities for understanding the human body, delaying the search for treatments and cures means leaving thousands behind, often unable to be productive and active members of our society. In fact to quote from the Centers for Disease Control website : "Indirect costs of poor health ... may be several times higher than direct medical costs and productivity losses related to personal and family health problems cost U.S. employers \$1,685 per employee per year, or \$225.8 billion annually." Between scientific opportunity to improve lives and the positive impact on the American people, investment in health research funding is an obvious choice for the better.

In closing, I urge you to consider what action you can take to make a difference for so many [or to vote for/against Bill #].

Sincerely,

[Your Name
& address if not already on your letter]

Tips and Resources

1. Find your elected representatives or heads of government agencies: <http://www.usa.gov/Agencies.shtml>
2. Or, go to the National Organization for Rare Disease – MGFA is a member – at <http://www.rarediseases.org/advocacy/hints-contacting-reps> where you can find links to US Senators and Representatives and tips on advocacy.
3. Learning more about the impact of chronic illness on productivity: <http://www.cdc.gov/workplacehealthpromotion/businesscase/reasons/productivity.html>
4. Draft your letter – keep it short and direct with essential details such as the bill you are supporting and/or a few compelling and relevant facts. See the sample letter included here.

MG Vaccine?

Foundation Focus reached out to Dr. Jon Lindstrom, Medical School of the University of Pennsylvania, whose work, along with co-investigators, has focused on the possibility of a vaccine for MG as reported recently in the *Journal of Immunology*. For more on this work also see *What's Hot off the Press in Neuromuscular Junction Disorders?* by Nicholas J. Silvestri, MD and Gil I. Wolfe, MD on page 20.

1) What do you see as the significance of your results so far?

We have devised a way to specifically suppress the pathological autoantibody response to muscle nicotinic acetylcholine receptors (AChRs) in the animal model of MG. Experimental autoimmune myasthenia gravis (EAMG) is caused by immunizing rats with AChRs purified from the electric organ of *Torpedo californica*. Vaccination of rats with the parts of human AChRs hidden from the immune system on the inside of muscle cells inhibits production of pathological autoantibodies directed at the parts of the AChR exposed on the outside of the muscle.

Vaccination prevents development of chronic EAMG and quickly and completely suppresses ongoing chronic EAMG. This suggests that this therapeutic vaccine would be effective on human MG. This therapy should be safe because immunization of normal rats with the therapeutic antigen does not cause EAMG. The therapy should be robust because the therapeutic antigen includes the cytoplasmic domains of all subunits of muscle AChR, so it does not depend on subtleties of immune responses to a single short peptide that might vary between individuals. The therapy should be long lasting because treated rats were resistant to re-induction of EAMG six months later by re-immunization with *Torpedo* AChR. Because the therapeutic vaccine is human AChR, it may work even more potently on humans than it does on rats.

What needs to be done before testing this therapy on human MG is to determine the best human-compatible adjuvant. We have been using a mild adjuvant used in animal studies (incomplete Freund's adjuvant). Alum based adjuvants usually used in human vaccines should work similarly. Ideally, we would like to test this formulation in EAMG to optimize dose and immunization schedule. Then we would like to test it on naturally occurring MG in cats to prove that it works on MG and further optimize dosing. This all depends on getting further grant support.

2) In the future, do you see this as a preventative vaccine or curative one, or both?

We see this as a curative vaccine that would suppress ongoing MG and prevent its recurrence. In principle, vaccination should prevent MG, but MG is rare so it would not be practical to preventatively vaccinate against it.

3) If someone you loved had MG, what would you say about the likelihood of a vaccine sometime soon?

We are anxious to see the vaccine available as soon as possible, but this may take several years. This will depend on getting support for further research, first in animals and then in humans, and on having the experiments work out as we think they will.



The Myasthenia Gravis Foundation of America, Inc (MGFA) is pleased to announce the creation of "my MG," an innovative mobile application (or "app") that gives people who have Myasthenia Gravis

(MG) a new tool that enables them to track their MG. "My MG" is a software application designed to run on Smartphones, tablet computers and other mobile devices for use in daily life. On the MGFA website, www.myasthenia.org you have all the main features of the "my MG" application along with an option to print a full report of the survey data you have recorded.

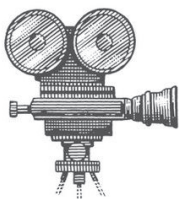
Using the "myMG" app to record MG symptoms and other notes enables you to have a more interactive and productive dialogue with doctors. Go to the Survey Tab to record your symptoms and how they affect your daily life. Record any notes that you think may explain changes in your symptoms (change in meds; forgetting your meds; ran a marathon).

Go to the Charts Tab to see how your survey results change over time. When you are ready to visit your doctor, use the Charts Tab to print surveys recorded since your last visit.

"My MG" puts the MG-QOL15 and MG-ADL tools into the patient's hand.



**Learn
something
new!**



Join MGFA for a live webinar or connect with a recorded one. See the MGFA website, <http://www.myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx> for current offerings. Keep your eye out for new announcements via email and the website.



**DOUBLE YOUR
MONEY!**

That's right increase your impact through your company's charitable match program. Many companies have a matching gift program, find out and when next you make a donation to the Myasthenia Gravis Foundation of America (MGFA) get it matched and make that much more of a difference toward overcoming MG.

**Introducing the
newest editions of
the Azathioprine,
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Unraveling the genomics of Myasthenia Gravis

Daniel Drachman, MD

Professor of Neurology and Neuroscience

WW Smith Charitable Trust Professor of Neuroimmunology

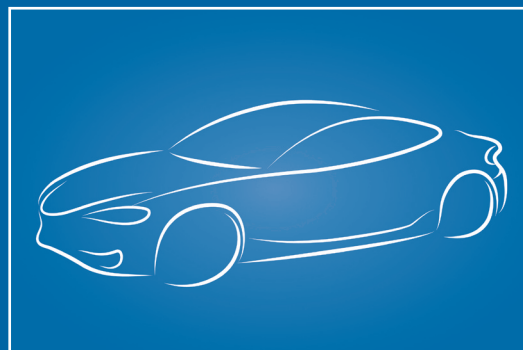
Johns Hopkins School of Medicine

This article describes a genome-wide association study (GWAS) of over 1,000 North American myasthenia gravis (MG) patients and 1,900 neurologically normal controls, supplemented by a follow up study of nearly 500 Italian MG patients and 500 controls. By analyzing these data, we have identified **three genetic loci** as being highly significant and important in the pathogenesis of MG. Our findings are based on comparing over 8 million genes from MG patients with those of the controls, and looking for differences. (called “SNPs” which stands for single nucleotide polymorphisms). Whenever, a researcher does a genome study, a mathematical expression is generated. It indicates how likely it is that the phenomenon is real. In this case, the likelihood that the results are wrong is less than one in 500 million. We have also identified nineteen other potentially abnormal SNPs that will require evaluation with even larger cohorts of MG patients.

The genes identified in this study are all related to the immune system, and they include the CTLA4 gene on chromosome 2, HLA-DQA1 on chromosome 6, and TNFRSF11A on chromosome 18. These genetic abnormalities have been replicated in the independent cohort of Italian MG cases and controls. CTLA4 (cytolytic T lymphocyte antigen 4) is important as an “off switch” that is present on activated T lymphocytes, and turns them off. Experimental animals that lack CTLA4 develop severe overproduction of lymphocytes and autoimmune diseases. HLA-DQA1 is a protein that is involved in presentation of antigens to lymphocytes. And TNFRSF11A encodes a protein that increases the immune response.

Our findings are exciting, and will impact patient care in a meaningful way. These results have several implications: First, they confirm the importance of genetic factors in the pathogenesis of MG. Second, the data are likely to have immediate therapeutic implications for the medical management of patients, as FDA-approved drugs targeting the effect of CTLA4 are commercially available and are used in patients with the autoimmune disorder rheumatoid arthritis. Clinical trials of these drugs in MG patients will undoubtedly be prioritized based on the results of our genomics project. Third, another finding of this study concerns differences in the genetic abnormalities in patients with late onset of MG (after age 40) as compared with patients first developing MG at an age of less than 40.

Donate Your Car to Fight MG



Do you have a car you'd like to get rid of?

Would you like to support MG patients and caregivers and MG research?

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Just donate your car to the Myasthenia Gravis Foundation of America.

You'll benefit by reducing your taxable income when taxes are itemized. Plus you avoid the costs associated with selling your car. No need to pay for advertising, no loss of privacy and possible security risks, no need to pay for vehicle registration, insurance, and repairs to keep your car running while waiting for a buyer. To learn more about donating your car, even your motorcycle or boat go to <http://www.myasthenia.org/HowcanIhelp/Donations.aspx>, under **Donations**, and look to #4 for links to more info and a donation form. It's as easy as that!

The Ellsworth Society



The Ellsworth Society is named in honor of Jane Dewey Ellsworth, our organization's founder. Ms. Ellsworth launched the MGFA in 1952 when her daughter Patricia was diagnosed. At that time, little was known about myasthenia gravis

and there were few resources for patients and their families. Today, MGFA touches the lives of hundreds of thousands of patients, families, friends, and medical professionals across the country and around the globe.

An Invitation to Join The Ellsworth Society

Members of The Ellsworth Society have expressed their commitment to Myasthenia Gravis Foundation of America through a very special and important form of financial support.

These donors have named MGFA as the ultimate beneficiary of a planned gift. Such gifts might include a bequest and/or charitable income gifts, such as charitable gift annuities, charitable remainder unitrusts, charitable remainder annuity trusts, or gifts of life insurance.

Once you complete your estate plans, please fill out our member profile form to let us know. We would like to thank you for your generosity by including you in The Ellsworth Society.

Membership Benefits

Your membership involves no dues, obligations, or solicitations, but it does allow us to thank you and recognize you for the plans you have made, and it may inspire generosity in others. You will receive a commemorative Ellsworth Society pin.

The most important benefit you will receive from joining The Ellsworth Society is the satisfaction derived from making a lasting contribution to MGFA's long-term prosperity and our ability to help patients and support research.

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Share your story:**

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Foundation of America**

**On our website,
Twitter
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**[www.facebook.com/ Myasthenia Gravis
Foundation of America, Inc.](http://www.facebook.com/MyastheniaGravisFoundationofAmerica)**

See you there!



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www.myasthenia.org

Myasthenia gravis is an autoimmune neuromuscular disorder. Symptoms may include double vision, drooping eyelids, slurred speech, difficulty chewing and swallowing, weakness in arms and/or legs.

MGFA is committed to finding a cure for myasthenia gravis and closely related disorders, improving treatment options, and providing information and support to people with myasthenia gravis through research, education, community programs, and advocacy.

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If you would like to receive Foundation Focus by email only, please email mgfa@myasthenia.org.

Thank you

...to all of our
wonderful
donors!

*Your generosity
brings us closer to a
world without MG.*

The goal of the MG Walk Campaign is to expand into new markets where we can bring together patients, create a community of active/engaged MG families and raise vital awareness & funding for myasthenia gravis! It is crucial that we go where we know we can garner the support needed to ensure success. If you are interested in seeing the MG Walk come to your area and you are excited to play an active part in its planning, promotion and production, we want to hear from you! Please contact the MG Walk Office at 1-855-MG-WALKS or Info@MGWalk.org or fill out our interest form found online at www.MGWalk.org. Thanks so much!

